

“Focus Group Participant Quotes”

Special thanks to the SCDA – MI Patient Advocates

Tracie Conic

Ben Frazier

Tiffany Chatman

Ruth Shovan

Linda Carter

&

MDCH Intern Lauren Lapine

“Knowledge is power.”

“Doctors see my list of medications and won’t treat me. I went a whole month without the meds I need.”

“He (emergency room doctor) messed up 10 times on me (attempting IV).”

“They (ED staff) ask me the same questions every time. They should be able to have those questions in the computer.”

“I don’t get a lot of pain crisis. My fear at the time was I want to live long. My grandfather is 93 and I want to live as long as him. I had concerns (about hydroxyurea) because of the side effects like gaining weight and losing hair. Talking with (doctor) helped me look at it not as just pain management, but more as longevity.”

“How many milligrams do I have to take a day?!”

“I had a bad pain episode and I paged day treatment and they called me back and said to come in. I was able to bypass ER and got immediate treatment and I was able to get the care I needed.”

“I took my son to Chicago for his birthday one year and he had a crisis. We sat in the ER for hours because they didn’t know what to do and how to treat it.” I sent a letter to the head doctor because I was so upset about how long it took for us to get seen.”

“The American Academy of Pain says you should have pain meds within a certain period of time and that amount of time is almost double for people with sickle cell disease.

“Adults with sickle cell teach children who have it. They go to their homes and pick them up and bring them to the Center.” - Reference to Project Enrich

“I have 3 children with special needs and do not get any resources, even though I adopted a child. Other states get more resources.”

“Sickle cell patients are labelled as drug addicts.”

“My son was going to the hospital frequently. His doctor said that he was a good candidate for hydroxyurea. He had some adverse effects early. Now his pain crises are far less frequent. He still gets some headaches, but we’re working on it.”

“The services across the board, from the clinics to the hospital rooms, we need more money. For years I have been told we don’t have the money to do that.”

“When my son starts a new grade, I take literature about sickle cell disease to the principle and teacher. I meet with them to talk about how sickle cell disease works. I give them a documentary to watch too.”

“Project Enrich allows for children to get one on one attention and provide them with adequate education and what it means to live with sickle cell. It helps them to not fall behind in school.”

“Sometimes it’s all about getting the exam done and no attention is paid to children. This is an important part of transitioning from childhood to adulthood. Patients must be able to give their own patient history in order to receive the care they need. There is a resident at Children’s now advocating for the transition between childhood and adulthood. More focus is put on children being able to report their own patient history and knowing where to go for care and how to make an appointment.”

“No one pays attention because we’re black people.”

“(In the emergency department) You may get someone that’s experienced, and you may get someone who’s not.”

“There’s constant judgment in the emergency department.”

My issues are with the ER. The lack of knowledge of the medical professionals about the disease is appalling. On a scale of 1 – 10, it's like a negative 5. They talk to you like you have no education, like you are some kind of perceived group and you have no sense at all. It's a consistent issue. I don't know if it's medical school, I don't know. If you have a comprehensive center, you should be very well versed. It's very poor treatment of the disease in the first place."

“We’re just the step-children of disease, certainly blood diseases.”

*“My son knows where it’s easier to get a vein.
They don’t give him enough respect because
they think he doesn’t know his own body.”*

“One of the big goals is to help people who have sickle cell disease be able to make an educated decision on whether they want to have children or not.”

“They (emergency room staff) don’t know very much and what they know is wrong.”

“They (emergency room staff) sent me home because they thought I was a drug addict. I was having a pain crisis and I took morphine and waited an hour and it didn’t work. I went and got blood work and they said you have morphine in your system. I said yeah because I was in pain. They sent me home. I came back and the hematologist recognized my pain and they admitted me.”

“My son hides his pain. He is 12 years old. They think he wants to miss school. He wants to go to school.”

“Even someone that’s a drug addict and has sickle cell disease is in pain. They still need medications.”

“Why can’t there be a greater degree of education for people who are going to work in a hospital in an area with a higher concentration of a specific disease like sickle cell?”

“There should be a standard protocol for treating sickle cell patients in the emergency department.”

“Some doctors are justifiably afraid to treat sickle cell patients. It is a labor intensive disease and sickle cell is so multi-symptom.”

“Sickle cell disease is not important – they put us at the bottom. I am going to keep fighting until we get everything we need.”

“I’m happy with my doctor. He doesn’t show any racism to me or my daughter. He doesn’t have that god complex.”

“When we lived in New York, there was an emergency department protocol in place. My daughter received great care immediately. I wonder if this is a Michigan or Midwest thing? All she does in (city) is wait to get care.”

*“When I went to (city) I got care immediately.
This does not happen in (city).”*

“Are you reaching out to (city) doctors? They’re the ones who don’t get it. Those are the doctors who should come to your meeting.”

“The reason people are addicted to drugs is because they were not treated properly in the first place, so they sought out something to take care of that pain.”

“They just assume because of their skin color that they are addicted to drugs.”

*“You can die from brain disease and you can die from sickle cell disease, but we are put below it.”
Professionals do not see sickle cell disease as life threatening.”*

“Maybe patients that don’t have a strong family support could have a patient advocate to come in and help talk for themselves.”

“I think something should be put in place where if they (patient) are having a crisis and don’t have any support they (patient) could call someone and have them be their patient advocate at the hospital.”

“We don’t wear our symptoms like people with cancer.”

“My daughter does great on hydroxyurea, She hasn’t had a pain crisis since December. She has a GloCap that reminds me to give her the medication. Before she took the drugs, she had crises every month.”

“My daughter does great on hydroxyurea, She hasn’t had a pain crisis since December. She has a GloCap that reminds me to give her the medication. Before she took the drugs, she had crises every month.”

"I use the Short-Stay instead of emergency department. I can call them at any time and they will get me in that day. When I get there, they hook up my IV fluids right away. There's a bed and room ready because they have standing orders and my doctor has already arranged the orders when I get there. This is something I discussed with my doctor and it was set up. It takes 5 hours total. My pain meds are ready. Nausea meds, pain meds, and Benadryl are all ready. A chest x-ray is ordered just in case as well. They (short-stay) treat other illnesses and ER cases there as well, not just sickle cell disease. If my blood work comes back and it's below 6, they have instructions to transfuse 2 units of blood. There are only nurses that work there and they just fill the doctors' orders."

“Since I’ve been going to Short-Stay, I don’t get admitted to the hospital as often.”

“When I was a child all of the doctors and nurses felt bad for me having sickle cell disease. They were nice, thought I was a cute kid. Once I hit 18, all of that stopped and I was treated totally different. That’s when they started saying I was a drug addict and there was nothing they could do for me.”

“As an (adult) patient, you have to start critiquing your own thinking and how you react to things (medical care). I cannot react to things (medical care) as an adult like I did as a child.”

“We were born with this. Our parents had the trait or the disease. We did not have a choice.”

“I would rather have a baby than have a sickle cell crisis.”

“People need to know the importance of donating blood for sickle cell disease.” I’ve gotten so many blood transfusions, that my doctors have to look all over to find blood for me. It can take 3-4 days. I’ve build up different antibodies so it makes transfusions difficult.

“(Patient Advocate) is like my big sister. She gives me information and I want to learn.”

*“I’m a first time parent of a child with sickle cell.
Education is very important.”*

“It’s not a one day disease, it’s a life-long disease.”

“Sometimes you have to be firm with the doctors. They are looking at it from a medical standpoint, not from a parent’s standpoint.”

“Last July there was blood drive with Red Cross specifically for sickle cell. It was great because it only focused on sickle cell. Part of the blood drive was to test people for whether or not they had the trait.”

“There is a 1% chance of developing cancer with hydroxyurea, and I’m not having that.”

“I’ve never heard of hydroxyurea. What is that?”

“Once you leave peds, you are totally on your own.”

“No one has ever talked to me about transitioning. (Patient Advocate) helps me now.”

“(Hematologist) is the best.”

“I’m teaching my daughter to be her own advocate.”

“My son is 19 but still sees his pediatrician. Who can I talk to about transition because he’s old enough now?”

“My son missed a lot of school when it got cold out. The school almost penalized him for missing school, but he was able to graduate.”

“I see (doctor). I like him a lot.”

“I’m happy with my care at (hospital).”

“My son’s immune system is weak so I try to stay away from the ER with him.”

“When I go to the ER, I immediately tell staff that I need someone who knows about sickle cell. I get in very quickly.”

“I don’t understand why there is not a protocol already in place to help people automatically transition from peds to adult care. Why don’t they just transfer his records and history to someone in adult care?”

“(Hospital) is stepping up their game. They’ve gotten more knowledgeable since I started going there.”

“20ish boys do not like to talk about sickle cell disease. I wish there was some kind of support group where my son can talk to other people.”

“I tell people to get in contact with (doctor) because he knows what he’s doing and they(doctors) do not.”

“The clinics need better communications.”

“My son was diagnosed at birth. I’ve lived in 5 different states and (city) is very far behind. When I lived in California, all of the doctors he needed to see were in one location. Now I have to take him to all different doctors. It’s not streamlined.”

“When I was transitioning my care, I had to make a lot of calls that I was not prepared for.”

“Having only one hematologist in the area makes it difficult when he goes on vacation or is unavailable.

“CSHCS is very helpful with billing issues.”

“My mom would call the hematologist when I was a child and then that person would call the ER and get them in the room right away. Now that I’m an adult, I don’t know what to do as much because my mom did everything for me before.”

“Transitioning requires a relationship between parent, patient, and provider. Preparing your child is essential.”

“I feel like I was handed to the wolves. When my cousin turned 15, two hematologist started seeing her together. An adult and pediatric hematologist. Then the pediatric hematologist just faded out and it was a seamless transition.”

“In (city) I’m just told who I need to call. It’s not even really a referral.”

“I didn’t know there was a difference between a primary care provider and hematologist.”

“I feel like I’m penalized for making good choices and my husband having a good job because I don’t qualify for CSHCS or any similar programs.”

“There needs to be more education in schools about sickle cell. My son kept having accidents in school because his teacher wouldn’t let him go to the bathroom.”

“My daughter is in her senior year of high school and she is just now getting an IEP. Since having an IEP in place, she gets extra time on tests now and extra time for homework.”